



PRODUCTIVITY COMMISSION INQUIRY: NDIS COSTS SUMMER FOUNDATION RESPONSE TO THE POSITION PAPER

The Summer Foundation made a submission to the issues paper in March outlining the current challenges and opportunities for the NDIS in meeting the needs of young people in Residential Aged Care (RAC) or who are at risk of being forced into RAC.

We stressed that the National Disability Insurance Scheme (NDIS), when designed correctly and implemented effectively will transform the lives of people with disabilities and assist Australia to meet its human rights obligations. By increasing socio economic participation, the scheme will also provide significant improvements to Australia's economy, raise the shamefully low employment levels of people with disabilities and carers and increase our nation's GDP. By providing individualised funding and shifting control from service providers to people with disabilities, economic efficiencies will follow, as consumers chase value for money and achieve greater outcomes.

We explained how young people in aged care are facing significant barriers accessing the scheme as well as problems developing and implementing their NDIS plans. The bureaucratic processes in the NDIS as well as a lack of service expertise and appropriate housing are preventing hospitals from discharging people with disabilities with complex health needs back into the community.

We advocated for:

- An end to that pipeline of entry into aged care with a strategic plan for discharge from hospital to the community through an effective NDIS plan, facilitated by expert designated staff who are responsible to prevent transfers of young people from hospital into aged care.
- Information and education at the coalface of discharge planning, and liaison roles that can oversee smooth transition of supports between sub-acute health and the community. People with complex support needs leaving sub-acute services require flexible and responsive supports that can respond to changes in a timely way, and their needs may change rapidly, requiring input from both health and disability providers, especially in the period immediately after discharge.
- A coordinated effort across sectors to meet complex health and disability needs. It is not always clear which sector should be delivering a particular service. For people in rehabilitation after trauma or injury, the split of responsibilities between systems result in delays in service delivery and an inefficient service response. For younger people in aged care to have good outcomes, a jointly resourced approach across health and disability sectors is more efficient and effective than the current cross referral pathways.
- Repairs to the broken interface between health and disability so people can live healthy lives in the community and to prevent costly hospital admissions.
- An effective pathway into the NDIS, for young people in RAC by making this group a designated "program" and bringing forward support for young people in aged care who live in the last rollout sites.

- Increased support to strengthen the capacity of people with disabilities with complex needs to make the most of the NDIS. It is critical to develop understanding about how to prepare for planning and how to make informed choices about housing and support.
- Capacity building of individuals and their families to self manage to maximise value and participant satisfaction.
- Health outreach services that provide 24 hour on call nursing with staff trained to work effectively with people with complex disability and health needs.
- Nationwide access to slow stream rehabilitation, transitional health services and ongoing support coordination for complex clients with changing needs.
- Housing that is accessible, affordable and adaptable to the specific needs of people with complex disabilities.

We pointed out that the lack of suitable housing is a significant barrier to moving young people out of RAC and a major reason why they are remaining in hospital unnecessarily or moving into inappropriate institutionalised settings. The delay in introducing SDA payments, the hold-up in these payments being issued and market uncertainty around quality safeguards has meant that very few housing options have been made available. This has meant that funding packages cannot be effectively utilised as the person remains in a nursing home or hospital bed with nowhere else to go.

We demonstrated that, for young people in aged care, who have complex support needs, planning is a difficult process. This is not a group, generally, who can navigate the NDIS pathway independently. We showed how there are significant inequities emerging because of the varied skill levels of planners, the amount of advocacy or supports an individual can access to prepare for planning, and the hasty haphazard manner in which plans are being developed.

We are pleased that our concerns with respect to the quality of planning were taken up by the Productivity Commission but would have liked to see more of the issues faced by young people in RAC reflected in the position paper. In this submission, we have outlined the key positions that we agree with and provided additional information where this was not available previously.

Pace of the rollout

We agree that scale and pace of the National Disability Insurance Scheme (NDIS) rollout to full scheme is highly ambitious. We believe that the NDIS is failing to deliver quality outcomes for participants because the Agency and partner organisations do not have the resources to deliver the quality of planning necessary within the timeframe specified in the bilateral agreements.

In response to information request 9.1, we do not support the slowing down of the rollout but we do support an increase in the resources available to undertake quality planning with participants. If the commission did decide to slow down the rollout, we would want to see young people in Residential Aged Care (RAC), or those at risk of entering, to have early access to the NDIS and to be exempted from an “across-the-board” slow down.

Prioritising access to the NDIS for young people currently in RAC and diverting young people with disabilities away from RAC and into appropriate housing with the right supports in place will result in cost savings for the health system and for the NDIS in the long term. This is because, once in RAC, young people experience deterioration in their health, a loss of skills and their social networks diminish. Preventing new admissions is a much more efficient use of resources than letting young people be admitted to RAC and then moving them out.

We know that young people in RAC are often highly susceptible to secondary conditions. These secondary medical conditions include pressure areas (31%), contractures (31%), urinary tract infections (23%) and chest infections or pneumonia (18%). Periodic admissions to acute health services are common – 42% of young people in RAC are admitted to an acute hospital each year, with some people experiencing multiple admissions (Winkler, Holgate, Sloan, & Callaway, 2012).

We also know that young people in RAC generally lead impoverished lives, characterised by loneliness and boredom. Fifty three per cent receive a visit from a friend less than once per year and 82% seldom or never visit their friends (Winkler, Sloan, & Callaway, 2007). They are effectively excluded from society with 45% seldom or never participating in leisure activities in the community (Winkler et al., 2007). Young people with disability living in RAC are one of the most marginalised and isolated groups of people in our society and we should do everything that we can to divert their entry to, and support their exit from, RAC as soon as possible.

Slowing down the rollout for young people in RAC would be both cruel to these people and also result in higher costs in the long-term as their needs will increase as they continue to deteriorate. Therefore, any proposed slowdown should exclude this group and instead, this group should be prioritised for early entry into the scheme.

Participant readiness

In response to the information request 8.1, we have real concerns that support coordination is not being appropriately implemented to meet the aims for which it was designed.

The Summer Foundation recently conducted an Environmental Scan of Support Coordination (Ellis & Fulton, 2017). We found that support coordination was struggling to meet its objectives. The common themes were:

- Inconsistent allocation of Support Coordination
- Excessive administrative responsibilities
- Lack of investment in training and development of Support Coordination
- Lack of clarity of expectation around capacity building
- Challenge of focusing on capacity building

Inconsistent allocation of Support Coordination

The allocation of Support Coordination in a participant's plan is reported as both incredibly varied with a lack of transparency about how allocation principles are applied. This generates a

feeling that there is inequity. Some report also seeing huge reductions in allocation in subsequent plans despite a continuing and genuine need for support.

Those who do not receive Support Coordination will then receive plan implementation support from a Local Area Coordinator (excluding WA). Anecdotal Participant experiences would suggest that both the allocation and expectations of navigating the implementation phase for plans is complex and confusing.

An illustration of the experiences some Participants are facing is captured in the below excerpt from an email from a Participant's nominee

“My son has been approved for NDIS but (and I am a qualified accountant with 40 years experience and have worked in 15 countries) I can't understand the process from here nor what his approval letter entitles him to. I am sure any new process has teething problems and time issues but calls to the help line have failed and I would appreciate any assistance in moving forward as his sole support.”

Excessive administrative responsibilities

The administrative support that Participants require assistance with can be arduous, including the initial translation of what their plan actually includes and can look like in reality (often resulting in renegotiation with the Agency), setting up MyGov account and understanding and navigating the portal.

In addition to the set up administration, many Support Coordinators are reporting significant time being spent in rectifying poor plans that do not represent the Participants' requirements. The NDIA states that Support Coordinators “do not make a judgement about the adequacy of the plan and do not make requests for an unscheduled plan review on behalf Participants”. Nevertheless Support Co-ordinators report on the amount of time overall that is being spent on rectifying inadequate planning at the Agency level, and this impacts on their work in reaching Participant outcomes.

The problems encountered with the introduction of the Portal have also been significant and continue to require a level of focus from Support Coordination that is again not recognized in people's plans. This level of administration support that Participants require can become a significant focus of their total supports coordination, leaving little room for capacity building.

Lack of investment in training and development of Support Coordination

Effective support connection will depend on the skills and growth of this workforce. Support Coordination allows for people with lived experience to offer this support as well as those with professional experience and/or qualifications. However there is significantly limited evidence of training or educational resources for Support Coordinators' development.

The lack of leadership and investment in the development of Support Coordination leaves the quality of Support Coordination unclear. Throughout this project, Support Coordinators reported a lack of information, training and or development opportunities to best develop their practice.

This is particularly evident in relation to the provision of technical advice such as the kind of assistance self managers require regarding employment advice or Participants who experience multiple systemic barriers – for example, young people living in nursing homes.

A support coordinator stated that:

“If you want to build a person’s capacity you need to understand a person’s cognitive, executive and communication impairment so you can use strategies to support the person with complex disability to engage meaningfully in the process and build their capacity”

This represents a large gap and opportunity for learning and development of Support Coordinators.

Lack of clarity of expectation around capacity building

One of the markers described by the NDIA for the NDIS is that ‘people with a disability are increasingly engaging in the economic, social and cultural life of the community’. They are becoming active citizens, are more resilient, develop support options that are more enduring and build ordinary lives strengthened by relationships, not just services (NDIA, 2015). This is a significant measure and one that requires a significant focus in how we support people.

This focus should run throughout all of the person’s interactions with the NDIS and could be a measurable element of the Scheme’s success. This is signalled as a large element of the Support Coordination function. There is, however, minimal understanding of what capacity building activities look like and what measurements can be adopted to signal success. There is much confusion about what capacity building approaches are expected within the functions of Support Coordination, including how to measure and demonstrate capacity growth. Work to explore effective strategies and measurements would be a worthwhile investment.

Challenges of focusing on capacity building

Capacity building is a named outcome of Support Coordination. People reported difficulties in getting to undertake capacity building activities because of the difficulties described above, the day-to-day demands of the role which can often entail a lot of problem-solving, and because of the level of unmet need and lack of quality, foundational supports in Participants’ lives, all of which take dedicated time to achieve.

‘Change doesn’t take one year’ was a common sentiment.

Addressing adaptive barriers to change is often a longer-term support. When people are seeking to be the author of their own life, many things have the potential to de-rail this. Change can be frightening and can be hard to imagine.

Time is needed to build relationship, move with people through the ups and downs of what it entails to make change and really see things through.

As one person reported, “The success with which an NDIS plan is implemented is directly related to the amount of time and effort that is dedicated to building-up a picture of a persons needs and wants / likes and dislikes”.

It would be useful to collate data on effective capacity building strategies and their timescales to better understand what this takes.

Planning

We agree with the Productivity Commission that the National Disability Insurance Agency should:

- Implement a process for allowing minor amendments or adjustments to plans without triggering a full plan review
- Review its protocols relating to how phone planning is used
- Provide clear, comprehensive and up to date information about how the planning process operates, what to expect during the planning process, and participants’ rights and options
- Ensure that Local Area Coordinators are on the ground six months before the scheme is rolled out in an area and are engaging in pre planning with participants.
- Ensure that planners have a general understanding about different types of disability.
- For types of disability that require specialist knowledge, there should be specialised planning teams and/or more use of industry knowledge and expertise.

Boundaries and interfaces with the NDIS

We agree that with the Productivity Commission that:

- It is a false economy to have too few resources for Information Linkages and Capacity Building, particularly during the transition period when it is critical to have structures in place to ensure people with disability (both inside and outside the National Disability Insurance Scheme) are adequately connected with appropriate services. The health, ageing and housing interfaces are especially important for our cohort and need significant upfront investment to build the capacity to respond to the needs of young people with severe and complex needs. Upfront investment is needed to:

- improve the discharge planning process so that young people exiting acute care in hospitals are not diverted into the aged care system.
 - Provide community-based health system responses to people with disabilities and complex health care needs including access to slow stream rehabilitation.
 - Improve the capacity of residential aged care providers to connect people with the NDIS
 - Develop the housing sector to respond to the needs of people with disabilities to live in the community.
 - Develop an evidence base to inform policy and practice with respect to disability housing and support. This would be best achieved through a co-ordinated approach similar to the [AHURI](#) model.
- The National Disability Insurance Agency should report, in its quarterly COAG Disability Reform Council report, on boundary issues as they are playing out on the ground, including identifying service gaps and actions to address barriers to accessing disability and mainstream services for people with disability.
 - Each COAG Council that has responsibility for a service area that interfaces with the National Disability Insurance Scheme (NDIS) should have a standing item on its agenda to address the provision of those services and how they interface with NDIS services. This item should cover service gaps, duplications and other boundary issues.
 - Through the review points of National Agreements and National Partnership Agreements under the Federal Financial Relations Intergovernmental Agreement, parties should include specific commitments and reporting obligations consistent with the National Disability Strategy. The Agreements should be strengthened to include more details around how boundary issues are being dealt with, including practical examples.

Provider readiness and pricing

We agree with the Productivity Commission that the Australian Government should:

- immediately introduce an independent price monitor to review the transitional and efficient maximum prices for scheme supports set by the National Disability Insurance Agency (NDIA)
- transfer the NDIA's power to set price caps for scheme supports to an independent price regulator by no later than 1 July 2019.

We agree with the Productivity Commission that the body tasked with price regulation for scheme supports should:

- collect data on providers' characteristics and costs. This should include appropriate funding to continue the business characteristics and benchmarking study currently undertaken by National Disability Services and Curtin University
- determine transitional and efficient prices for supports at a state and territory level

- comprehensively review and publish its price model on an annual basis. This review should be transparent, have public consultation, be evidence based and evaluate the effectiveness of prices in meeting clearly defined objectives
- assess and recommend when to deregulate prices for supports, with particular regard to the type of support and region, on the basis that prices should only be regulated as narrowly, and for as short a time, as possible.
- Be supported by an independent, funded research body that commissions applied research that can provide strong outcomes based evidence to inform pricing, similar to the [AHURI](#) model.

We agree with the Productivity Commission that a market based model for disability supports, thin markets and market failure is likely to result without the necessary for the market to develop and be sustained. The participants most likely to be affected:

- are living in outer regional, remote and very remote areas
- have complex, specialised or high intensity needs
- who have an acute and immediate need (require a rapid response).

Participant and mainstream sector readiness

We agree with the Productivity Commission that it is a false economy to have too few resources for Information Linkages and Capacity Building (ILC), particularly during the transition period when it is critical to have structures in place to ensure people with disability (both inside and outside the National Disability Insurance Scheme) are adequately connected with appropriate services.

We agree that funding for ILC should be increased to the full scheme amount (of \$131 million) for each year during the transition. The funds that are required beyond the amounts already allocated to ILC to reach \$131 million should be made available from the National Disability Insurance Agency's program delivery budget.

We also agree that the effectiveness of the ILC program in improving outcomes for people with disability and its impact on the sustainability of the National Disability Insurance Scheme should be reviewed as part of the next COAG agreed five yearly review of scheme costs. The ILC budget should be maintained at a minimum of \$131 million per annum until results from this review are available.

Governance

We agree that with the Productivity Commission that:

- The National Disability Insurance Agency should publicly report on the number of unexpected plan reviews and reviews of decisions, review timeframes and the outcomes of reviews.

- The performance of the National Disability Insurance Scheme (NDIS) should be monitored and reported on by the National Disability Insurance Agency (NDIA) with improved and comprehensive output and outcome performance indicators that directly measure performance against the scheme's objectives.
- The NDIA should continue to develop and expand its performance reporting, particularly on outcomes, and Local Area Coordination and Information, Linkages and Capacity Building activities. The NDIA should also fill gaps in its performance reporting, including reporting on plan quality (such as participant satisfaction with their plans and their planning experience, plans completed by phone versus face to face, and plan reviews).
- Responsibility for funding National Disability Insurance Scheme (NDIS) cost overruns should be apportioned according to the parties best able to manage the risk. This is not the case in the transition period, as the Australian Government bears all the risk of any cost overruns, but not all the control.
- The Australian Government should reconsider the staffing cap on the National Disability Insurance Agency, especially during the transition period, given that the current restrictions are impacting on the quality of planning, information for stakeholders, strategic thinking and active market stewardship.

Funding Arrangements

We agree that with the Productivity Commission that in-kind funding arrangements should be phased out by the end of transition and should not form part of the intergovernmental agreements for full scheme funding.

With respect to in-kind funding arrangements, we are especially concerned that NDIS Rules are being established restricting participants to in-kind options. Namely, the Plan Management Rule and Section 4.2 of the SDA Rule.

Section 4.2 of the SDA Rule sets out a process where participants are first offered only in-kind SDA vacancies, which they will be required to accept rather than being able to access other more suitable housing options. This upholds Plan Management Rule 6.9 that where an in-kind support is available to be provided to a participant that the participant's statement of participant supports must specifically identify that the support will be provided by the relevant provider of that in-kind support. This approach unreasonably restricts participant choice and makes State Governments 'providers of first resort' with first choice of all participants with SDA in their plan.

These rules undermine choice and control for NDIS participants. For people who are currently living in State government properties, this appears to restrict their ability to leave a state government group home. They are against the Principle (e) of the NDIS Act that the NDIS will "enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports". This also contradicts the Convention on the Rights of Persons with Disability which says people with disability have the right to "choose their place of

residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement” (Article 19).

Preferencing in-kind breaches the principles of competitive neutrality and sets up a captive market that will jeopardise much needed improvement in the quality of housing and support for people with disabilities. It inhibits the market’s development by creating an uneven playing field between existing in-kind housing and new market providers, including people with disabilities themselves, wanting to develop new and innovative housing options.

The NDIS can make a real difference to the lives of people with disabilities and their families by addressing the unmet need for housing and support. For this to be realised, up to \$5 billion of new SDA housing is required. This will be made more difficult if new accommodation providers understand that they will only get referred tenants if no State Government in-kind vacancies are available. The result will be a reduction in the quality and quantity of SDA housing, which will be detrimental to participants and exacerbate the problems faced by the NDIA in addressing the under-supply of quality SDA housing options.

REFERENCES

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